



The LincPIN

The **L**incolnshire **P**ost-Polio **I**nformation **N**ewsletter
Volume 6 - Issue 1 — May 2007

WebSite - <http://www.lincolnshirepostpolio.org.uk/>



Photos from MIAMI PPS CONFERENCE

Dual screen with contemporaneous transcript.

Above right: Prof. Mike Kossove, Organiser
Barbara Gratzke & Prof. Walter Bradley.

Below: Tatiana & Luiz Baggio Neto
from Brazil.

Below right: Phyllis Mass & Mary McCreddie.



AGM - September 15th 2007



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Lincolnshire Post-Polio Network - UK Registered Charity No. 1064177

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DONATIONS.

Grateful thanks to all that has been received. Names will be added next newsletter.
Sincere apologies for not including the names in this issue due to Hilary requesting
this information late, and our Treasurer is away from home.

Lincolnshire Post-Polio Network - UK Registered Charity 1064177
Donations large and small towards our work are always welcome.

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Next LincPIN Newsletter - August 2007

Articles for publication 4th July by post or - newsletter@lincolnshirepostpolio.org.uk

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Editorial by Hilary Boone.

I apologise for the delay in your receiving this Newsletter. I have been told that the older you get the faster time goes as you have more time behind you as experience. Time is just whizzing by some days and I am finding that I am getting less done than I could have done last year. I wonder has becoming an 'Old Age Pensioner' got something to do with it?

The Miami PPS conference was excellent in content and a great chance to meet 'old' and new PPS friends. Sharing of information has and always will be the best way to gain more knowledge about the issues that arise and how others have dealt with them. Two great things came out of the PPS Conference. The first was new initiatives to work together with other PPS groups and the second Dr. Walter Bradley, Professor and Chairman Emeritus of the Department of Neurology, University of Miami congratulated me on the work I had done on the Mayo Study and has offered to work with us. More on that soon.

In this newsletter you will find 'Ask Dr. Perry - Revised' article authored by Mary Clarke Atwood of the Rancho Los Amigos PPS Group in California. Dr. Perry has decades of experience of polio and post polio issues and authored many articles.

Joyce Kelly from California offered us the story of her polio life. For me, who remembers nothing of my polio age 5 and little of my growing up years, this gave me some idea of some of the things I might have experienced at school and medical appointments. I just blocked it all. I have included this because so many are reluctant to talk about those years, not only polio survivors but family members as well. Our parents do not really want to open their box on our polio past. Our siblings most probably were too young to really understand what was happening. It might be helpful for your family and friends to read what it was like to have been in our shoes.

Following that I have included - with permission - the text of an excellent email by Sandra Cuadra about how we need to pace our 'emotional life' as well as our physical life. This triggered many other emails about the stress that many of us have experienced from health professionals who are lacking in knowledge and understanding of PPS. If your health professionals have not corroborated your symptoms is it any wonder many of us report family members also thinking 'it is all in our minds'.

When some folks wished me a good time on the Cruise that followed the PPS Conference I realised that I must have worded this badly. Unlike many Polio Survivors representing their PPS organizations neither Mary McCreadie nor I got any financial support towards the cost of the Conference, Hotel or Travel. Much as we would have loved to go on a Cruise afterwards the cost was way beyond our means. The only way I have been able to attend Conferences up to now has been from donations from my family and equity from my home that I really could not afford. We urgently need to raise funds to continue our work.

We would love to publish more of our members articles but to do this you have to write them so how about putting pen to paper, or fingers to the keyboard?

AGM reply slip page 13/14. You can send us the information by email, letter, cut the bottom part of the page from the newsletter or download pdf copy of pages 13/14.

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MESSAGE FROM YOUR ACTING CHAIR Mary McCreadie

Being thrown in at the deep end is sometimes the best way to learn – and that is certainly how my first couple of months being Acting Chair of our committee has panned out!

Quite apart from the normal duties required of the position, it also coincided with the Miami PPS Conference which I had decided to attend as soon as I heard about it. I had never been to a conference of this type before. It involved a major journey to America with all the associated bits and pieces such as getting my lost passport replaced, getting a photographic driving licence and making sure all the travel and hotel arrangements were in place. I found it all very exciting, but at the same time pretty daunting – especially as PPS has prevented me from travelling very far for a number of years. What I was not prepared for, was the length of time it has taken me to recover from such an adventure. I, of all people, having preached ‘pace and rest’ to everyone, found myself guilty of not doing so, and am still paying the price. Let that be a lesson to me!

The most important things to come from the conference for me, were the friendships and associations that we [LincsPPN] were able to make – which simply would never have been possible otherwise. Finding that our problems are the same world-wide, regardless of race, colour or creed, and that we are not ‘the lone voice crying in the wilderness’ really brought home the enormity of the dilemma.

World Polio Group. Many PPS support groups represented at the conference found themselves galvanised into forming The World Polio Group. The idea came from Kim Dowds, who is the Director of the March of Dimes, Canada. The aim is for PPS support group leaders to come together to share ideas and initiatives, so that polio survivors worldwide can speak with one voice. To this end, an e-mail list has been set up which enables members to talk with one another easily even though we live on different continents. One member - Luiz Baggio Neto - comes from Brazil, where if anything, PPS is even less recognised than it is in the UK. Luiz is the director of ABRASPP (Brazilian Association of Post-polio Syndrome). The group is fighting to get PPS recognised in the International Disease Catalogue ICD 10. If anyone is interested, details of ICD 10 can be found at: http://www.apheo.ca/indicators/pages/resources/ICD_10_CA.html

ABRASPP is also involved in attempting to educate health professionals and society about PPS, giving support to polio survivors, and trying to stimulate research. Sound familiar?

On the social side, it was really wonderful to meet so many polio survivors, and it would have been nice to have had more time to talk and reminisce, but attending the workshops and lectures were more tiring than I would have believed possible. However, I would particularly like to thank Phyllis and Herb Mass, a delightful couple from Fort Lauderdale. Phyllis runs the Fort Lauderdale PPS Support Group, which meets every other Sunday. Phyllis and Herb invited a friend and me to their home, and then treated us to a truly lovely

day out at Flamingo Gardens, a sanctuary for Florida wild-life and botanical gardens.

Greater contact with Members. A conversation with Linda Priest of the Atlanta Post Polio Association, about their new Care System - A team leader in each area - brought our own situation very much to mind. Last year, we were able to organise a little 'get-together' with our South-Western members. This was so successful, that we wanted to extend the idea to cover the whole of the country – but time, health and other commitments rather got in the way. No one person can cover the whole country, so the success of this idea depends initially on members of our Committee and Operations Team being prepared to host such events. Maybe you could be a host in your area? It takes time and effort to organise, even though it's only a 'little' meeting – but our feeling is that members everywhere might enjoy such contact.

We know that many of our members are not in a position to travel to any sort of meeting, and feel a little isolated. This could be easily solved by a regular phone call if it is what people would like. We certainly do not want to 'poke our noses in' if we're not wanted, but I know from experience how good it is to make friends over the phone with other Polio survivors. I am still in touch with a number of members whom I contacted about the South-Western meeting, and I value the time spent chatting with them.

It would greatly help us if people who think this would be a good idea, would let us know. A quick phone-call, e-mail or letter (details on inside cover) so that we can estimate the level of interest will allow us to decide on the best way to arrange things.

Incorrect volume number last newsletter. We have just noticed that the last newsletter has an incorrect Volume and Issue number. Hilary apologises for forgetting to change this. It should have read Volume 5, Issue 12 of 12. If you like to keep your LincPINs in order, please alter the number!

Our Annual General Meeting has been booked for 15 September 2007, at The Memorial Hall, 317 Newark Road, North Hykeham, Lincoln. LN6 9RY. This is the A1434 and the building is almost opposite the North Kesteven School and Sports Centre. All attendees will be sent tickets which will include two mobile phone numbers to contact during the weekend.

The plan for the day is to open the doors at 10.00 a.m. for an AGM start of 10.30. We anticipate from previous years that this will take about an hour.

Jean Murdoch will then speak on Direct Payments [Social Services assess you and you are then given a set amount of money to buy your own care]. Jean has just been featured in a county newspaper promotion of the scheme but also speaks from personal experience of some years.

Buffet Lunch will be served from approximately 12.30 p.m.

The Afternoon session, starting at 1.45 p.m. will be workshops with health professionals in attendance. This is a two way process:-

- giving you a chance to air the issues and problems you have had with assessment, advice, treatment and equipment, which will give the health professionals present a much wider overview of what is occurring
- receiving advice from the health professionals as to possible solutions

We look forward to another full and interesting meeting, and hope that as many of you as possible will be able to attend. Further details in the next newsletter. For those of you who need to stay overnight, The Ibis Hotel is convenient, and well used to people whizzing about in wheelchairs and scooters! The address is: Ibis Hotel, Runcorn Road (A46 off Whisby Road) Lincoln, LN6 3AZ. Tel: 01522 698333. State member of LincsPPN. It is a good idea to book early! We will be holding Get-togethers in the Bar of the IBIS hotel both Friday and Saturday evenings.

Nominations On pages 13/14 you will find a nominations and attendance form for the AGM. You can send us the information by email, letter or cut the slip from the page. Please return it to us by 31st July 2007. Many thanks.

Funding. During the ten years that LincsPPN has been operating, the time, effort and money that has been devoted to our Charity by the committee and Operations Team have been phenomenal. The work that they have done, and everything they have achieved, would in the 'real' world have cost tens of thousands of pounds, and deserves proper recognition. However, I can offer only a public thank you, to all concerned – both past and present. Lincolnshire Post-Polio Network would not exist, were it not for your valuable efforts.

Funding is an ever-present worry, and we are looking for someone who would be prepared to assist in attempting to raise substantial funds. It takes time, dedication and a certain amount of knowledge. If anyone feels that they could help us in this, then please contact us as soon as possible. The more funds we have, the more we can do to further knowledge of PPS and raise awareness.

The Mobility Roadshow is probably the world's largest event of its kind, and is *the* annual national motor show for disabled people. There will also be a showcase of a great variety of products and services to aid an independent lifestyle. The Mobility Roadshow aims to give anyone with a mobility problem the chance to assess what is available to help solve that problem and most importantly to try out and evaluate the options in a 'no pressure' environment. The Show will be held on Thursday 19th, Friday 20th & Saturday 21st July 2007 at Kemble Airfield near Cirencester, Gloucestershire. Opening times are: Thursday & Friday 10am- 5pm, Saturday 10am-4pm. It's an ideal opportunity for as many of us as possible to get together as well. Hilary, Richard and I will be attending, and suggest that we all meet on the Saturday at 2 p.m. It's difficult to pick a suitable meeting place without seeing the layout, or knowing the state of the weather for the day. If everyone who wants to join us lets us know we will get back to you. If you decide at the last minute, forget or get lost then we will ensure the folks on the BPF stand (No.D22) know where we are. We look forward to seeing you there!

Mary McCreadie. mary.mccreadie@lincolnshirepostpolio.org.uk

Email Forum

The e-mail forum has proven itself to be a great medium for supporting our online members, especially when things are worrying them. I was really glad that so many of our 'listers' were able to offer empathy, experience and encouragement to member Anne Wood, who had to have an operation recently. Hospitals are not the nicest places to be in, especially when you are afraid that the staff won't understand the particular needs of a polio survivor. Add to that the possibility that the consultant or anaesthetist may not recognise or know how to deal with possible breathing problems during such an op, and it can be really worrying. Despite a more complicated operation than expected, everything seems to have gone well, and Anne has just let us know she is back home and doing well.

This incident happened to coincide with a draft initiative from the Neurological Alliance and other associated bodies. They have drawn up a document entitled 'What you need to know about my condition', and it is specifically aimed at providing medical staff with information about the patient's needs during a stay in hospital or perhaps a convalescent home. It is very simply written, and gives the opportunity to list in detail what you do or do not need. I was so impressed with the idea, that I printed out the draft and filled it in – just to see if it was as good as it looked. Little did I know that three days later I would be rushed into hospital too! I took the filled in form with me, and gave it first to the ambulance crew who used the information to fill in their forms. Their reaction was a heartfelt 'I wish everyone had one of these!'

Having all the relevant information in black and white meant they didn't have to ask me when I wasn't in a fit state to give sensible answers, and there was no chance of mishearing or misinterpreting. The ward staff were also delighted with the form as it made my needs clear and easy to understand. Unlike my last incarceration in hospital, I didn't have to keep explaining to each and every individual that I couldn't walk – especially if they took my elbow-crutch away from me! We have worked hard over the last two weeks on an adaptation of this form for Polio Survivors, which I am pleased to say we have included with this newsletter.

As usual many different subjects have been discussed, including a Post Polio Course at St. Thomas' Hospital in London, which member Glenna Tomlin is attending. We look forward to hearing all about it.

The list did go 'quiet' a few times. I always hope that when we have quiet times, it means that you are all out enjoying yourselves.

You may not realise quite how much your posts help others who read them – even if those people don't actually contribute. So keep on writing! If you haven't yet joined our on-line community, you can do so by sending an e-mail to

join-pnl@lincolnshirepostpolio.org.uk.

Remember if you are not online you can write to us or if you need to talk to someone then give our Phone Team a ring on 01522 888601. A message will give you the number of the Duty member who will help you find an answer to your questions.

Mary McCreadie mary.mccreadie@lincolnshirepostpolio.org.uk

Ask Dr. Perry - Revised

With Jacquelin Perry, M.D.

Reported by Mary Clarke Atwood

Rancho Los Amigos Post-Polio Support Group Newsletter-May 2006

Editorial assistance by V. Duboucheron, J. Perry, M.D.

Updated March 2006

Our thanks to Dr. Perry for so graciously taking the time to review and update these responses. Since retiring after 40 years of dedicated, full time county service, polio specialist Dr. Jacquelin Perry continues her work at Rancho but in a new capacity -- as a volunteer consultant. The Rancho Los Amigos Post-Polio clinic continues to be a source of excellent care each Friday afternoon due to the commitment of two other excellent physicians. Dr. Sophia Chun is the current chief of the clinic; her medical training includes both internal medicine and rehabilitation. Dr. Vance Eberly is an orthopaedic surgeon. Both attend the clinic regularly and Dr. Perry is there frequently. Dr. Perry also volunteers as a medical consultant to the Rancho Los Amigos Pathokinesiology Laboratory. She no longer gives lectures.

Question 1. What is the natural progression of post-polio syndrome? Will a person return to the same degree of paralysis that was experienced at onset?

Answer: When focusing on the natural progression of PPS it is important to understand that muscle function depends on three systems:

Control from the brain

Sensation from the periphery

The lower motor system from the spinal nerve cell (anterior horn cell) down to the muscle.

The third system is the most important for people with PPS because if you lose the nerve, you lose the muscle. We talk about muscle weakness, but polio is actually a nerve disease that damaged or killed anterior horn cells. This makes a lot of difference in terms of exercise, etc.

Acute: During the acute phase of polio some spinal nerve cells died while others were injured but later recovered. Some people had paralysis but others did not. The effects were like spatter paint. If you had a lot of "paint" you had a lot of damage, while others were just touched lightly. But all survivors were left with a damaged neuro-muscular system.

Recovery: Recovery from polio entailed all three methods of recovering function:

Neuro recovery

Between 12% - 91% of the nerve cells that were injured by the poliovirus recovered.

Axon sprouting

New branches of the remaining nerve cells were sent out to adopt the orphaned muscle fibers. The result was that each nerve was then doing 50% more work, or even up to four times as much as normal.

Hypertrophy

The muscles enlarged themselves up to about 40% so they could increase function.

It is not known how much a survivor's recovery was due to spontaneous nerve generation, nor how much could be credited to patching by the axon sprouting, nor what amount was due to hypertrophy. Upon recovery polio survivors had a random disability in regard to the amount of paralysis. The amount of muscle weakness a person had was pure chance; it depended upon the amount of poliovirus a person had and where it went. Some survivors remained paralyzed, while others looked or felt normal although they were not.

Research: During the 1940s Bodian traced the poliovirus in the motor nerve cells of monkeys. He found that polio, a systemic disease, affected 95% of these cells by either injuring or destroying them. Research confirms that there is some obvious weakness as a result of polio:

Agre found that polio survivors with no current symptoms had only 80% of normal muscle strength. Symptomatic survivors had 60% or less muscle strength compared to the normal group.

Following a four-year study Grimby reported a normal 2% - 5% loss of muscle strength in asymptomatic polio survivors, but for symptomatic survivors this loss may be as high as 13%.

A study by Grimby confirms that weaker muscles work longer and twice as hard.

An electromyographic study by Dr. Perry also confirmed that weaker muscles work longer and twice as hard.

This research says that it is necessary to protect an overused muscle system. The muscles that are grades 3, 3+, and some 4s are getting all the exercise they can tolerate. In order to maintain this function these muscles must be protected from overuse. Dr. Perry added, "New damage is prevented or curtailed by being active, but avoid getting tired. When fatigue begins, STOP and rest. Two 20-minute rest periods a day preserves one's endurance."

Now: For many, many years polio survivors have been working with a damaged neuro-muscular system that keeps working harder than ever to meet normal demands. We need to appreciate the fact that each anterior horn cell innervates several hundred muscle fibers and the surviving horn cells have been doing 50% more work than normal. Plus it appears they don't like being overworked!

Because of this overuse of the neuro-muscular system, new weakness is now developing. Survivors may develop new weakness not only in "polio" muscles but also in other muscles that did not seem to be involved during the acute phase.

Although the amount of weakness a polio survivor develops in later life depends upon the original involvement; age is also a factor. Anterior horn cells do not have infinite durability -- they begin aging at about 60 years of age. So polio patients aged 70 and up have a natural weakness just from age that needs to be appreciated and put in perspective also.

Question 2. Do you know of any research on treatments for PPS?

Answers:

Mestinon: There was a six-center study of the drug Mestinon (pyridostigmine) in 126 patients. Mestinon acts at the nerve-muscle junction by changing the chemistry and making the connection last longer. For many years this drug

has been used for myasthenia gravis patients. Since Grimby's research has shown that polio survivors can overuse the nerve-muscle junction, the use of Mestinon for some polio survivors makes sense to Dr. Perry.

In this 1995 Mestinon study, Dr. Daria Trojan reported that there was trouble getting statistical significance, but the best correlation between Mestinon and relief versus the placebo occurred in subjects who had 25% or less normal strength, i.e. muscle grades 3+ and down. Dr. Perry believes Mestinon has a role for those who are quite weak, but for people with grade 4 muscles and up she has observed no improvement with its use.

Anti-inflammatory Drugs: These medications have been Dr. Perry's mainstay because the first reaction to muscle overuse is inflammation. These drugs take away the added insult from having overdone but they are not pure pain medicines. Dr. Perry does not use pain medications per se for PPS because they only mask a person's overuse and do not help that problem. She wants patients to control their lifestyle and not overdo and thus avoid the pain of overuse.

Growth Hormones: These drugs have been found to relate more to muscle function than to nerve control. They seem to parallel function rather than control function. No significant changes have been found for polio survivors.

Question 3. Are you familiar with electro-stimulation for polio survivors?

Answer: The answer is yes and the answer is no. The easiest way to stimulate a muscle is to use one that has a nerve. Therefore, this involves the nerve-muscle junction. Electro-stimulation has been tried on a few polio survivors at Rancho with no affect; Dr. Halstead, a polio survivor affiliated with National Rehabilitation Hospital in Washington, D.C., tried it on himself with no affect; several of Dr. Perry's patients tried it at Dr. Pape's office in Canada with no affect. So electro-stimulation is not an answer. Post-polio patients' problems are with the nerves.

Exercise: Some researchers in other parts of the country favor exercise for certain polio survivors. I observed that their research has been done in parts of the country that have bad weather -- so their subjects already have about 3 months disuse due to climate. Here in Southern California we do not have disuse because of bad weather. If disuse of muscles does exist, then exercise may be needed. But if there is no disuse, such as here in Southern California, exercise is not indicated.

Question 4. Can trauma be a trigger for PPS?

Answer: The answer is yes. Following an acute injury there is a period of disuse during recovery. Up until the time of injury a person's strength has been built up very gradually. There is an old saying that says, "If you can lift a calf every day, when you become an adult you can lift a cow. But don't ever stop." This phrase is saying that if you got a very small amount of increased exercise on a regular basis (as the calf got larger) you built up yourself gradually. But don't ever change the model. As soon as you stop, there is no way you can exercise that gently anymore. It is very difficult to recover on a therapeutic basis after that. Once there has been an injury the model has been changed.

Question 5. Does spinal stenosis occur earlier for polio survivors?

Answer: Spinal stenosis is the thickening of bone around the spinal canal. It does

occur in natural society but it is not very common. I have not seen any PPS patients with spinal stenosis.

Question 6. Could you give us some tips for putting less stress on our upper extremities?

Answers:

Problem 1: Shoulder pain develops in crutch users.

What does a crutch do? It supports body weight. The more weight, the more it goes on your hand, elbows, and shoulders. When the normally powerful shoulder depressors (pectoralis major, etc.) wear out, the shoulder takes the strain and the supraspinatus tendon gets impinged (pinched). This impingement cannot be prevented. Pain indicates it is time to ride -- in a wheelchair or scooter if appropriate.

Problem 2: Upper arm pain when reaching overhead.

Reaching overhead uses two muscle systems. A person can avoid overhead reaching by using a reacher when necessary and by not placing things above the shoulders. Find other activities that do not involve shoulder use.

Problem 3: A person's arm dropping away from the socket (usually about 1/4 - 1/2 inch).

Slings don't usually work well because they hang from your neck. I prefer to use a gunslinger apparatus to help support arm and shoulder. A gunslinger is a device that rests on the hips/pelvis area and has one or two attached pieces to support the forearm(s).

Some patients use a fannypack [U.K. bumbag] under the arm for support.

Problem 4: Shoulder and neck pain when working at a desk.

When working at a desk, do not lean forward to do your work. Instead, try to lean back ten degrees so gravity is helping your muscles. Bring your work to you.

There are three things a person can do to relieve the strain on the upper body muscles:

Eliminate reaching

Support the arms

Break up activities

Advice: Listen to your body. Feel the aches and pains. Then do something about it. **"Be an intelligent hypochondriac!"**

Question 7. When should we use cold packs or hot packs?

Answer: Cold for 5 minutes or less is good. It breaks up the edema formed by overuse. Then follow with heat for 10 minutes and REST a while.

Question 8. Are you sending any PPS patients for acupuncture?

Answer: I am not sending anyone for acupuncture although some patients are trying it and getting help. It is not going to do any harm. The reason I do not prescribe it is because I do not have any indication of whether it will help or not

help. When I make a prescription I would like to know the outcome.

Question 9. Can PPS be part of a weakening heart muscle?

Answer: No, PPS cannot be part of a weakening heart muscle. The muscles and nerves to the heart are a different system so there is no direct connection to PPS.

A person can be deconditioned by not being active, but if you are not strong enough to be active your heart does not have to be that conditioned. So don't worry about it. Just don't get fat and do avoid cholesterol!

Question 10. How can a polio survivor control muscle twitching and/or cramping?

Answer: Muscle twitching is a sign of overuse. It can happen to anyone, not just people with PPS. Cramping is also a sign of overuse. A polio survivor needs to change his lifestyle to avoid overuse of muscles. [Conserve it to preserve it.]

Question 11. What are your thoughts on hip or knee replacement surgery?

Answer: For an arthritic hip, total joint replacement is just fine if you have the muscles to control it. A polio survivor needs to have about grade 3+ hip muscles for this surgery to be successful. Otherwise the hip will dislocate.

The knee is simpler to handle because it can be put in a brace since it is a tubular structure. But there is no brace for a hip.

Question 12. How can sleep problems be helped?

Answer: A study on sleep disorders compared people with PPS to average people. Both groups had the same problems -- restless legs, etc. I suggest that, before going to bed, people get themselves comfortable, warm, and perhaps take 2 Advil (or something like that) to get rid of the aches and pains. If a person awakens in the middle of the night, it may be helpful to get up and start again. Half the world has trouble sleeping all night. This is not unique to polio.

If a polio survivor has been diagnosed with sleep apnea it is probably related to breathing or swallowing problems from PPS.

Question 13. Is there any connection between polio and meningitis? When I was a baby my parents were told I had meningitis. Several years ago a doctor told me I never had meningitis but I had polio.

Answer: Meningitis is an inflammation of the coverings of the spinal cord and brain. Polio is an infection of the anterior horns of the spinal cord. The inflammatory reaction also involves the meninges. At one time it was called polio-encephalomeningitis. It was actually an involvement of the whole system. The main way of identifying polio was with a spinal tap. If it got into the anterior horn cells it was called polio. There are a lot of neurological problems that are not highly defined, but can be identified by lesions revealed during autopsy.

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The Trustees meet twice a year in person and via the Internet at other times by mutual arrangement. If you would like any more information then please ring or email. You may nominate yourself for any Trustee position. The Operations Team—non-Trustee posts—are listed on page 2. If you have a few hours a month to spare and would like to join them and support our work then do please get in touch.



Nominations are requested for the following Trustee positions:-

Chair

Vice Chair

Secretary

Treasurer

Committee Members (4)

A copy of this reply slip (pages 13/14) can be found at
www.lincolnshirepostpolio.org.uk/downloads/extra/agm2007replyslip.pdf

AGM is FREE. Full day including buffet lunch £4 – Without lunch £1.00

Rooms are available at the IBIS Hotel just off the A46 Bypass on 01522 698333

All rooms are now Non-smoking and priced at £48. [1 or 2 guests] 10% discount for Ibis Loyalty Card Holders. Continental breakfast ‘eat all you want’ range of bread rolls and pastries, bread for toast, juice, yogurts, cold meats & cheeses, hard boiled eggs, cereals, fresh fruit is £5.25 per person.

Snacks are available. Take Away’s are permitted. Full meal service in Pride of Lincoln next door, Frankie and Bennies Italian eatery next to that.

Social Evening Get To-gether’s will be held as in previous years both Friday and Saturday night in the Bar of the IBIS Hotel.

If you live locally and are able to offer accommodation please contact us.
There are B&B’s in the area but we do not have information as to their accessibility.
Contact Lincoln Tourist office on 01522 873256 or 01522 873213.

Why not share a room or transport? If you would like to join up with others then please let us know so that we can put you in touch.

Questions for the AGM or afternoon workshop can be included at bottom of this page.

IWOULD LIKE TO / WILL BE / WILL NOT BE
Attending the AGM on September 15th in Lincoln.

Address
.....
..... Telephone Number.....

Accompanying me will be

I enclose £ for tickets.

I enclose a donation of £ [First class stamps always welcome]

Dietary request

I would like to share transport/a room if at all possible. I am Male/Female.

QUESTION FOR THE AGM
.....
.....

SUBJECT I WOULD LIKE TO RAISE/BE RAISED AT THE AFTERNOON
WORKSHOP.
.....
.....
.....
.....
.....



Growing Up With Polio in California by Joyce Kelly.

joyjoykelly2@yahoo.co.uk

I was born in 1957 in Los Angeles County, California. At the tender age of four months old I came down with a very high fever and as it subsided my mother noticed that I was no longer moving my legs. I was diagnosed as having contracted the poliovirus. My mother told me that the doctors tried all sorts of medical techniques on me such as wrapping my legs very tightly with elastic bandages, supposedly to help keep my muscle tone intact, and other things that did not work. She also told me how all the neighbours shunned our family after it was known that I had had polio.

By the age of two I was taught to walk with a brace on each leg and use crutches. At age three my legs had not gained back their natural strength so I was given a surgery to cut the ligaments in my legs. This was to keep the atrophying muscles from causing severe leg bone curvature during my growth and development. I can recall being in the hospital for that surgery. Mostly I remember my toys falling out of the bars of the hospital crib, and being lonely. I had no idea what they were doing to me even though I could see the incision wounds on my legs.

I do not remember being conscious that I was "crippled" or "different" as a toddler, but I do remember the braces being very uncomfortable especially when they had a bar attached from ankle to ankle to keep my legs stretched away from each other for some reason. I also remember always having to go to therapy but it had not dawned on me that I was permanently going to be disabled. I had two brothers and three sisters, none of whom had caught polio, but still I did not realise that I was any different than they.

When I was about four years old my grandparents took all of my siblings and me to the Ice Follies. I loved the show and I remember looking up at my grandma, who was sitting next to me in the stands, and telling her that when I grow up I wanted to be an ice skater. My grandma just smiled back at me without saying anything. I had no idea whatsoever that I would never be able to ice skate. A few years later, although I knew I was paralysed from polio, I still did not fully realise the limitations that I would have during my life. At age nine I read a book about a young lady who became an airline hostess. I thought her life seemed very adventurous so I then wanted to be an airline hostess when I grew up. Even at nine years of age, I did not know that I could not become an airline hostess.

I became a Poster Child for the March of Dimes organisation when I was two years old. My photo was taken about once a year to be used as newspaper advertisements for the local Mother's March of Dimes fund raisers. I can remember having to go to a big annual square dance function to have my photo taken with the dancing club that was also sponsoring fund raising for March of Dimes. Sometimes the photographers would be sent to my school or clinic to take my photo. I did not think anything unusual about my photo being taken until I became five or six years old and began to be annoyed with it. The last time they took my photo was when I had to have it taken with some "old" ladies from some woman's club and I did not want to cooperate. The ladies wanted me to smile and smell some flowers, and I was just so disagreeable. In my mind, the ladies shoved flowers into my face, although I am sure they really did not go that far. The photo did get taken and

printed but I was never asked to do a March of Dimes photo shoot ever again.

One very obvious issue that had a great negative affect on me was that people were often staring at me. It made me feel uncomfortable. I often complained to my dad, "Those people are staring at me." My dad's reply became, "Well, if you were not looking at them you would not know that they were staring." So I began to be wary of looking at anyone in his or her face, even those who were talking to me. I protected myself from people's glares by looking down most of the time. I became awfully shy as a result of this. I assume staring was the strongest message I encountered which let me know that I was different and that being "crippled" was something to keep people from liking me.

In the 1960s in Long Beach, California, physically disabled children were not allowed to go to the "normal" public schools. We were sent to the "special" school where children with all types of physical disabilities were put. I really did not have any specific complaints about that particular school, but I wanted to be able to attend the same school that my brothers and sisters went to. I complained to my parents about going to the "regular" school but that did not do much good at first. In second grade (seven years old) I began to act out by refusing to read because I did not want to go to that school anymore. The teachers tried to coax me to read; they even tried to bribe me by sending me to the library by myself and having the librarian show me nice picture storybooks. But I was obstinate and I would not open a book no matter how tempting the cover looked. My schoolteacher called my parents concerning my behaviour. Finally, my mom decided to try and get me into the "regular" public school. She had to go to the school district offices. They did not believe that I would be physically capable of "regular" school, but in the end they agreed if a doctor of their choice examined me and thought I could manage "regular" school then they would allow me to transfer. I passed the examination and I was allowed to begin "regular" school the following year.

I made the transition into public school with few difficulties. I could not do all of the sports at recess—but I did fine. I even played Dodge Ball, both inside and outside of the circle! Only a few kids made fun of me, and that was because of the ugly shoes that I had to wear on account of my brace, not on account that I was paralysed. [At age three I was no longer forced to wear a brace on the right leg since it had about half of its muscle ability intact.] I was the only physically disabled child in the entire school and that was just fine with me because I was at the same school as my sisters and brothers. One boy my age did throw some small rocks at me on the way walking to school, which caused my leg to bleed. When I arrived to my class I told my teacher about it, but in those days little was done, if anything, about these types of incidents. It was just considered teasing. I was not emotionally scarred for life; however, I still remember the boy's name, which I otherwise probably would not have.

My peers in junior high school were less accepting of me, but I think that was more due to the awkward stage kids at that age are going through. Many adolescents will tease anyone who is different than what they think individuals should look like. I do not remember any other students with crutches in junior high school other than those who were recovering from accidents. During the junior high school years I was tripped on purpose (by Mike Lawson—I remember his name too), had food thrown at me during lunch by a group of girls (the type who smoked cigarettes in the lavatories—so you'd just expect that type of behaviour from them), verbally

teased quite a bit, and once had eggs thrown at me by a boy named Don. I went to the dean of the school and complained about that boy hitting me with eggs but he was not reprimanded at all. After awhile I just gave up on complaining to teachers and the school administrators and began staying home from school whenever I could. My mom would let me stay home and she or my grandma would write me notes that I was sick.

My fellow students in high school treated me much better, and during those years several other physically disabled students—even a few in wheelchairs were attending the public schools. There was a special “homeroom” for the disabled kids but I had bypassed it since I had been in the public system for six years by that time. A few times teachers would say to me, “Aren’t you supposed to be in the special homeroom for the handicapped students?” I did not care for their assumptions—it stereotyped me as handicapped, but their question did not seem to be meant as an insult. The laws to include handicapped children in public education had improved so much by 1972 that our school district in Long Beach, California, even had one class of driver’s training for those who needed hand controls to drive—this was before the big education budget cuts in California began to destroy the state’s education system; nothing free like that exists today. So I was taught to drive when I was 15 years old, received my driver’s permit, and had my official driver’s license by the time I was 16 years old.

The worst incident pertaining to my disability in high school came not from my peers, but rather from one of the administrators of the school, Mrs. Hale, known as Mrs. Hell to the students. One day as I was walking to class she stopped me so she could humiliate and accuse me concerning my disability. I was wearing a knit top with a cotton button down shirt over it tied at the waist. As now, and as I will always have to deal with, when I take a step with my crutches they often pull my blouse up—anyone who has had to use crutches will know about this. There was a rule at school that not a bit of skin could show at your waist, and I guess as I walked my crutches pulled up my shirt causing some skin at my waistline to become visible. Mrs. Hale said to me, “Don’t think because you are crippled that you can get away with breaking the school rules! Go home and change your clothes!” I did go home, but I did not come back that day. In this present age a student could bring a lawsuit against the school for an incident of verbal harassment and public humiliation such as that. I have never forgotten what Mrs. Hale said and how she said it with utter contempt; it stands out as the most unjustified thing that ever happened to me throughout all of my childhood.

The only other thing I wish to say about my time in high school is that I had a 3.97 grade point average and no counselor or teacher even took notice. By the time I went to a counselor at school on my own initiative to ask for scholarships to go to college—the counselor told me they were all taken. I did end up getting a small bond from the Lion’s Club, just about enough to buy two textbooks back in 1976. However, I thought that the high school would have been trying to guide a good student into college—but it was never mentioned to me. I was never called into a counselor at all and Long Beach high schools had many counselors in those days so I do not know why I was slighted. No teacher even suggested to me that I should go on to college or gave me any information how to find out about college and scholarships.

Graduating high school and turning eighteen years old in 1975 classified me as an

adult so I will end my childhood details and dilemmas at this point. I often wonder how much I was affected by the things that happened to me and by the things that were said to me as a child and teenager. I think it has a lot to do with why I hate to be disabled, along with all of the other reasons why being disabled is not a preferred existence such as pain, medical expense, and inability to do many tasks and activities. Unfortunately, the degrading by others does not stop just because the disabled person gets older. Actually, in my estimation it has become worse because people regard us as burdens that they are forced by law to accommodate and they take their aggravation out on us in other ways. Being paralysed from polio has caused me to be denied of so many things in life and to be treated as an inferior human being, and it continues to do so today.

Pacing our emotional stress by Sandra Cuadra, Florida.

biglol@VERIZON.NET

We frequently discuss the ways in which we can slow down and pace ourselves physically to stretch out and maintain our mobility. But, just as important is slowing down and pacing the effects of emotional stress we encounter.

Some one on a Polio list responded to an email by remarking that 'surely 30 miles was not too far to travel to visit G'pa more often.' I thought at the time that it isn't a matter of miles, it is a matter of emotional equilibrium involved here. Visiting G'pa may be very emotionally stressful. We may love G'pa to bits but only be able to take him in small doses.

I think we all may have family or friends that fall into a 'toxic' category, and because at one time we could absorb the stress being with these people may cause, we feel obligated to continue. This shouldn't be the case. When you have PPS, you are obligated to pick and choose stressful situations you will tolerate, and do everything in your power to avoid all others.

I no longer go to funerals. The dead don't care, and the stress involved is too high a price to pay. I remember the dead as they were in life, not in a box. I remember the grieving with cards, flowers and mementos, not my presence at such an emotionally charged event as a funeral.

I see family members who are 'royal pains in the ass' as little as possible, while before PPS, I would tolerate them whenever the need arose. I nurture my relationships with family that do not drain me emotionally and bring stress into my life. I am not saying we should put on rose colored glasses and shut out loved ones because we have PPS. On the contrary, I say we should look at our emotional life as we do our physical being and prune out the stress.

[Editors Note - This really hit home as I have virtually no relationship with my brother and now both parents have passed on wonder whether I will ever see him again, which saddens me. My last contact was a year ago when he told me by email that the reason we did not have a good relationship was because of my imaginary health issues. It upset me considerably, more so I realise now because of the huge amount of time I have given to LincsPPN work. Now I have calmed down enough to deal with this I now wonder should I just leave this or is there a way I could redress this without incurring too much stress?
hilary.boone@lincolnshirepostpolio.org.uk]

**Have you found any Aids and Assistive Devices
that might help us manage our lives more easily?**

Bathing - Soaking aching muscles is something we all want to do but many report they have been told that a flat floor shower is all that Social Services will support. Before making any decision you need to research all the options. It is imperative that you try before you buy.

Member Sandra Walline, had a video made of how she manages her life in her home, putting on a swimming costume for the bathroom filming. An excellent idea to demonstrate our 'HOW' to health professionals.

Dr. Lauro Halstead, one of America's top PPS Specialists - and a fellow Polio Survivor - advises that to ensure hand rails and accessories in the bath or shower are in the right place you need be wet before deciding.

Whilst searching for a new bath we found the following which we look forward to viewing in July at the Mobility Roadshow.

The WIBCO—Walk in Bath Company - Slide in Bath.

STOP PRESS - Stand D12 Mobility Roadshow July 19 - 21 2007.

Wibco state they invented the first ever walk-in bath with an inward opening door in 1996 are confident that this new approach will benefit many people. This new model can be used independently by anyone who has even modest upper body strength. If a carer is needed to help the bather, then very little effort should be necessary to assist the bather to enter and exit the bath.

Seat Height is the same as a wheelchair. No need for a lift or hoist. Anti slip base. No electrical power required. Easy installation. Double wastes for fast emptying. Supplied with a TMV3 thermostatic valve and taps, Height 1130mm (44"). Length 1315mm (52"). Width 700mm (28"). Available in white only.

They can only fit within 50 miles of Portsmouth but state that any competent Plumber can do this within a day and they are only a phone call away. The Universal bath, on a supply only basis delivered anywhere in mainland UK, is £2500.00 excluding VAT. The optional automatic hydrotherapy spa system is £599.00 + Vat. If the end user, or some one in the same household, has a disability (they do not have to be registered disabled) then the purchase price can be exempt from VAT, this is a simple procedure that only requires the signature of the user and description of the disability. We can supply 'Eligibility Declaration Forms' on request. This is a simple statement that will accompany your order confirmation.

http://www.wibco.com/walkinbath_Universal.htm

WIBCO, Unit B3, Mountbatten Business Park, Jackson Close, Drayton, Portsmouth, Hampshire, PO6 1US, United Kingdom

Tel: +44 (0)23 9237 2000 Fax: +44 (0)23 9238 4040

Why not write and tell us about your aids and assistive devices. Why were these prescribed for you/did you choose them. If, like Kathleen Burrell, you have made these yourself then please send details and photographs. What make of car/van and hoist/ramp/lift do you have? We would like to devote a LincPIN issue to this subject as well as it being our main AGM topic.



**THE LINCPIN
SEARCHES FOR AIDS
THAT MIGHT MAKE
OUR LIVES EASIER**

**SLIDE IN BATH FOUND
By WIBCO
See info page 19
and at the
Mobility Roadshow
July 19—21st
Cirencester.
Stand D12**

Dates for your Diary

**Mobility Roadshow
July 19th to 21st 2007
Kemble Airfield,
Cirencester, Gloucestershire**

**Meet other members at 2p.m. on Saturday 21st 2007.
See page 6.**

Additionally, Hilary and Richard Boone are booked in at the Swindon West Holiday Inn Express, just off junction 16 of the M4. They will be arriving mid-afternoon Friday 20th and leaving Sunday 22nd after lunch. So if you can't make 2pm on the Saturday, they would be delighted to see you at the Hotel sometime during week-end. Contact Hilary to arrange a date and time (see page 2 for contact details).



**Annual
General
Meeting
September
15th 2007**

**MEMORIAL HALL
317 NEWARK ROAD [A1434]
LINCOLN LN6 9RY**